

Back-to-School Kit

Acute Flaccid Myelitis (AFM)

Below is a brief summary of the disorder affecting your student. While the presentation of symptoms may vary, this overview provides general information on the onset and impacts of the disorder. We hope this information is helpful and assists you in supporting your student as they navigate the education system while also managing their condition.

What is acute flaccid myelitis, and who gets it?

Acute flaccid myelitis, or AFM, is a rare condition where there's inflammation in the spinal cord, mainly affecting a specific part in the center of the cord called the grey matter, which can cause sudden weakness or paralysis in arms or legs. Between 2012 and 2018, there were outbreaks of AFM every other year, particularly in summer and fall. We have not seen a spike in cases since 2018. While we're not entirely sure which viruses are causing AFM, there's a strong connection between these outbreaks and specific infections, leading to more research on these connections for both diagnosis and treatment. AFM mainly affects children under 18, with the average age being 6.3 years old.

What are the initial symptoms of AFM, and what are the chronic symptoms those with the disorder often manage long-term?

In AFM, there is an initial onset where the body attacks itself. The aftereffects of attacks can lead to life-altering long-term symptoms that the person with the condition will need to manage.

The initial onset of AFM will often start suddenly and can include weakness in arms or legs, trouble breathing or swallowing, and even difficulty moving the eyes. The weakness can get worse quickly, sometimes causing trouble breathing, so it's important to go to the hospital even if symptoms seem mild. AFM can cause mild to severe weakness in one or more limbs, often starting in muscles close to the body. Some may also have pain in the neck, back, or limbs. While sensation and bathroom habits are usually okay in kids with AFM, more severe cases might have issues with feeling or controlling the bladder and bowels.

What are common accommodations students with AFM might need to access education?

The accommodations necessary for children with AFM can vary depending on the severity of its impact on the child, but the following are accommodations more frequently requested by those with AFM:

- Physically accessible classrooms (weakness may prevent easy access to the classroom)
- Accessible workstations (may need space for mobility aids, or different space than peers)
- Alternatives to writing by hand (may have issues with holding a pencil and needs a different method of inputting answers)
- Adaptive tech that allows for writing (may use alternative methods to convey data and complete tests and homework)

What does short-term treatment look like for those with AFM?

AFM does not have a specific treatment, but doctors have been successful using intravenous (IV) steroids, IV immunoglobulin (IVIG), and plasma exchange (PLEX) to reduce spinal cord inflammation and stop the immune system from harming the body. IV immunoglobulin has antibodies that may help in fighting off the virus causing AFM. Results with steroids and plasma exchange vary. Since AFM varies in its presentation from person to person, treatment is customized. Starting physical and occupational therapy early helps prevent long-term problems.



What does the long-term management of AFM look like?

After the acute phase of Acute Flaccid Myelitis (AFM), the focus shifts to rehabilitation, which is critical for recovery and preventing complications. This phase often begins in the ICU and continues through a structured rehab program, targeting various areas including respiratory function, muscle and bone health, skin care, pain management, bladder and bowel function, mental health, and daily living skills such as dressing.

For students returning to school, it's important for families to address ongoing needs like special accommodations and support for physical challenges. Long-term management for families involves coordinating with medical professionals, acquiring necessary equipment, and reintegrating into school or community activities. Understanding the emotional impact of AFM on children and families is important as families will need to adapt to a new way of life post-hospitalization.

Those with AFM may experience long-term issues such as respiratory difficulties, muscle weakness, joint problems, and bladder or bowel challenges. Some may require ventilator support for breathing. Reduced movement can result in weakened muscles and bones, potentially causing fractures.

Mental health is also a significant consideration. Children with AFM might face depression or anxiety, which need to be monitored and addressed with appropriate support. A combination of education, therapy, and ongoing support helps both the child with AFM and their loved ones navigate the physical and emotional impacts of AFM.

What kind of recovery do people with AFM experience?

Recovery varies among individuals with AFM. Most do not recover fully, but some do regain strength and motor function over time to varying degrees. The most affected muscle may be the least likely to recover. Physical and occupational therapy are believed to be critical for recovery in AFM.

How can people cope with an AFM diagnosis?

Adapting to a "new normal" is difficult, and every person with AFM copes differently. Some have found it easier to cope after learning more about AFM from their doctors and getting a better understanding of how AFM will affect their lives. However, some parents may choose not to keep their child informed on some of the difficult aspects of having the condition due to the age and innocence of the child. We recommend speaking with the parents of the child to determine how much the child knows about their own condition.

Learn More

SRNA
wearesrna.org

Back-to-School Kit
Teacher's Guide
srna.ngo/bts-tg

More information on AFM
srna.ngo/afm

